



## **Living positively with HIV/AIDS-Miss Stigma Free**

*Dumela Magazine* met with Neo Chitombo in Stockholm, to talk about her insights on living with HIV/AIDS. Neo visited Sweden to participate in the 2009 book fair held in Gothenburg during September 24-27. She contributed a chapter, "I am Miss Stigma Free" in the book, "As an Invisible Stone in my Heart-about HIV and AIDS in Sweden and the world", published, in Swedish, by Leopard Förlag and launched at the fair. Other contributors are Swedish Prime Minister, Fredrik Reinfeldt, former President of Botswana, Festus G. Mogae, and various experts on HIV and AIDS.

In addition to Neo, about 20 other people living with HIV/AIDS, from various countries, contributed chapters to the book. At the book fair, Neo took part in seminars discussing stigmatization from her perspective of being HIV infected in Botswana. The seminars involved participation by notable persons such as author Henning Mankell, Mona Sahlin (leader of the Social Democratic political party in Sweden) and Lars Olof Kallings, Professor Emeritus of Medical Microbiology.

### ***Why did you decide to test for HIV?***

A friend confided in me about her status in 2001, by then she was very ill. She asked me to look after her baby if she passed away. Unfortunately I did not have the chance to take care of the baby who only lived for three months after the mother passed away. It took tremendous effort for me to test and, thereafter, I had no courage to receive the results. I visited the testing centre several times and finally dared to get the results 6 months after the test. I was shattered by the HIV diagnosis.

### ***What did you think when you got the diagnosis?***

I thought that was the end of my life. My friend had been advised by the hospital not to breast feed her baby. But she decided to act against the doctors' advice, to avoid speculations. She had many times said that she could not face stigmatization. Neither did I think I would have the strength and guts, and her death was my wake-up call.

***Why do you think there are prejudices around HIV infected persons?***

People always associate the transmission of the virus with sex, something that is perceived to be shameful. Notwithstanding that both my friend and I had lived a fast life, prejudices exist. Sadly, the secrecy around the disease has had other consequences: some of the elderly who care for their beloved ones end up being infected due to ignorance.

***You say that you stigmatized yourself. What do you mean?***



By keeping my status a secret, I behaved like all others who stigmatize the HIV infected. I was worried about what people would say. But then I decided to come out of my cocoon. I woke up to the reality that I had to live and see my children, two sons and daughter (born 2004), grow up. The wish to see my daughter get married weighed heavily on me. I had been talking about the disease in general, with my mother, but not about my diagnosis. When I finally got the courage to tell her, I was deeply touched by her reaction. In my mother I have a friend who continues to be the rock I can stand on when everything around me turns gloomy.

***What were the reactions you received when you went public?***

Like in any relationships with relatives and friends, I got mixed reactions. Some people were happy for me that I had tested, that I was getting treatment and that I spoke openly about my status. There were some skeptics who thought that I went public to get some recognition and monetary rewards, as I was not working at the time. I decided to focus on myself and my future. My mother was very supportive and continues to be. Whenever I would raise my fears about the negative public perceptions, she would say, “Neo, people will always talk but they eventually tire or shift focus to others. Just be you and everything will be fine. Such is life.” I decided to lean on my mother.



Henning Mankell and Neo Chitombo

***How can the environment be influenced by that one speaks openly about HIV positive status?***

Sharing a concern that can be a threat to people’s lives can never do any harm. The more people there are sharing experiences the better. There are people who have died because of ignorance. Our future is in our children and we should arm them with information that can help them make wise decisions.

***Is it important to be open about HIV status or should one treat it as a private matter?***

I consider it important to talk openly, even if it is not about our own status but in general. Why should we tell other people that we have blood pressure problems, cancer, diabetes, swine flu, or any other disease? It is important that we help each other as a society on issues that affect our health.

***Could it be argued that prejudices and the stigma around HIV/AIDS contribute to its spread?***

To a large extent, that may be the case. For example, information on the demography of the infected, say that statistics point to age group 18-25, may naively influence people to think that if they contain their relations within age groups outside this range, they may be safe. HIV/AIDS has no discrimination.

***What do you think it will take to continue to reduce the spread of HIV/AIDS in Botswana, despite the improvements seen in recent years?***

We should empower the children/youth with information to help them make informed choices. Children have to understand their own bodies from a very early age. They should get broader education to prepare to live an independent life, financially and materially. Some of the spread has been a result of desperation and the need to survive. The individual becomes like a butterfly whose survival depends on the wings that surround its body.

***How do the schools ensure that children get to know about HIV/AIDS?***

More and more children seem to be aware of HIV/AIDS through the school system. But there does not seem to be a systematic training for teachers to make sure that schools in general spread uniform information. Apart from HIV/AIDS, there are other support systems that are required for teachers to help children with special health needs. Generally, teachers tend not to have the training to deal with children with special needs, for example, allergies, asthma, or other health conditions. It is more critical to ensure that the school system through the curriculum and health programs are aware of how to care for children diagnosed of HIV and how they can be protected from stigmatization. More importantly, teachers should have up-to-date information about the disease.

To address this, each school should have at least one person designated to discuss HIV/AIDS and other life threatening diseases with children.

***How do you see your future and the Botswana society in general?***

At a personal level, going public has helped me plan for the future, longer term. I had given up on life. I have decided to live and to see my children grow and my daughter get married. There is so much to live for. I secretly carried the heavy stone of HIV infection in my heart for many months. It took a death of a friend to touch the stone and to decide to shake it loose.

At a societal level, I feel that there is more to be done. With the strong support of the free issuance of anti-retroviral drugs and the prevention of the mother-to-child transmission, Botswana has laid a good foundation for further work. There is a need for more people to get involved in discussions on HIV/AIDS and the education of our children on the dangers of the disease. Testing should be something that people do to know their status and to decide on what to do, without fear of stigmatization. Families should be encouraged to make testing part of family life in order to instill the importance of early diagnosis to children and the benefits that go with knowing one's status.

**Neo Chitombo** worked in a number of non-governmental organizations, mostly on voluntary basis. She later opened a day care centre, Bright Faces Day Care Centre, in Kumakwane, her home village, about 20 kilometers from Gaborone. She has 43 pupils and is assisted by two staff. The day care is struggling to raise funds.

**Julia Majaha-Jartby**, the interviewer, lives in Sweden following a career with the Bank of Botswana and the International Monetary Fund. She grew up in Masunga, a village in the North East of Botswana.



Julia and Neo

Photos: **Mats Ögren Wanger**